# Autism and bilingualism: A qualitative interview study of parents’ perspectives and experiences

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Parent perspectives on autism and bilingualism

Autism and bilingualism: A qualitative interview study of parents’ perspectives and experiences

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Parent perspectives on autism and bilingualism

Abstract

Purpose Research into how bilingual parents of children with ASD make choices about their children’s language environment is scarce. This study aimed to explore this issue, focusing on understanding how bilingual parents of children with ASD may make different language exposure choices than bilingual parents of children without ASD.

Method Semi-structured qualitative interviews were conducted with 17 bilingual parents with a child with ASD, and 18 bilingual parents with a typically developing child.

Results Thematic analysis revealed that, in contrast to parents of typically developing children, parents with a child with ASD expressed concerns that a bilingual environment would cause confusion for their child and exacerbate language delays. This was particularly common for parents of children with lower verbal ability. Parents also identified potential benefits of bilingualism, particularly in terms of maintaining a close and affectionate bond with their child.

Conclusions Parents of children with ASD have concerns about bilingualism not present for parents of TD children and these concerns are greater for parents of children with lower verbal ability. Future research in this area should take into account factors such as parent-child bonds, as well as communication and language development.
Parent perspectives on autism and bilingualism

Introduction

Bilingualism, which can be defined as the use of two or more languages, is a prevalent phenomenon worldwide (Grosjean, 2010) and a growing practice in the UK (Edwards, 2011). There is a sizeable literature reporting either cognitive benefits of bilingualism during typical development (Barac & Bialystok, 2011) or an absence of negative consequences on aspects of language such as onset of speech (Holowka, Brosseau-Lapré, & Petitto, 2002). Despite this, parents of typically developing (TD) children sometimes express reservations that bilingualism may cause confusion and hinder their child’s linguistic development (Dorner, 2010).

These concerns may be exacerbated for parents of children with neurodevelopmental disorders, such as autism spectrum disorder (ASD). However, there is a scarcity of research investigating how bilingualism might interact with such conditions. ASD is characterised by challenges in social communication and interaction, and restricted, repetitive behaviours and interests (American Psychiatric Association (APA), 2013). Children with ASD often experience language difficulties, with some remaining non-verbal into adolescence and beyond (Howlin, Savage, Moss, Tempier, & Rutter, 2014; Kjelgaard & Tager-Flusberg, 2001). For those who acquire language, delay in the acquisition of both receptive and expressive language may be apparent (Mitchell et al., 2006) and complications in the pragmatics of language – conversational rules, use of referential expressions, irony and metaphor – are common and may remain throughout life (Colle, Baron-Cohen, Wheelwright, & van der Lely, 2008; Happé, 1993; Surian, Baron-Cohen, & van der Lely, 1996).

Studies exploring the experiences of bilingual parents of children with ASD (predominantly residing in North America) have found that parents express concerns that bilingualism would be confusing for their child and would amplify language delays already present due to ASD (Kay-Raining Bird, Lamond, & Holden, 2012; Yu, 2013). The belief that
Parent perspectives on autism and bilingualism

bilingualism is detrimental for children with ASD tends to be shared by professionals, who
often advise parents to adopt a monolingual, English-only environment for their children
(Jegatheesan, 2011; Kay-Raining Bird et al., 2012). Given these considerations, parents often
make the switch to a monolingual environment after learning that their child has ASD
(Kremer-Sadlik, 2005).

At present, there is little empirical evidence available to help guide the views and
practices of parents and professionals. However, the notion that bilingualism is damaging for
children with ASD is not supported by the limited evidence available. Several studies have
found no differences in linguistic skills (including vocabulary and age of early language
milestones) when comparing monolingually and bilingually exposed children with ASD
(Hambly & Fombonne, 2012; Ohashi et al., 2012; Petersen, Marinova-Todd, & Mirenda,
2012; Reetzke, Zou, Sheng, & Katsos, 2015). There is also evidence that children with ASD
are capable of developing skills in more than one language (Hambly & Fombonne, 2012).
These second language skills may depend on various factors such as language exposure and
verbal ability. For instance, Hambly and Fombonne (2014) found that higher levels of recent
second language exposure and higher dominant language vocabulary were associated with
higher second language vocabulary for children with ASD. This may indicate that stronger
verbal ability and a greater level of exposure to a second language facilitate second language
skills for children with ASD.

Furthermore, it is possible that bilingualism could improve communication and social
skills in children with ASD. Valicenti-McDermott et al. (2013) found that bilingually
exposed children with ASD used more communicative gestures and engaged in more
imaginative play than their monolingual counterparts. These findings are consistent with
evidence that TD bilinguals outperform monolinguals on measures of social skills, such as
Parent perspectives on autism and bilingualism communicative gesture (Yow & Markman, 2011) and remedying breakdowns in communication (Comeau, Genesee, & Mendelson, 2007).

Thus we are faced with a situation where many parents, advised by practitioners, seem to be making the choice to raise their children in a monolingual environment, despite the fact that the (admittedly limited) evidence suggests that bilingualism does not confer disadvantage and may even yield advantages.

Another understudied but important factor is the effect of bilingualism on the emotional wellbeing of children with ASD and their families. For bilingual families of TD children in the US, there is evidence that maintaining the parents’ native language as the home language facilitates cohesive parent-adolescent relationships (Tseng & Fuligni, 2000). Kremer-Sadlik (2005) found evidence that these dynamics are also present in families of children with ASD. Parents who used only English with their child reported a decline in interactions with their child and a decline in the child's participation in family conversations. This may be because parents feel less restricted in their native language and as a consequence feel a closer bond with their child when using this language.

In addition, research investigating the impact of a minority (home, native) language versus a majority (community, official) language has revealed a vital role for the minority language in maintaining cross-generational relationships (Fishman, 2001), fostering group identities and preserving cultural heritage (Farruggio, 2010). It may be that this intimate link between the minority language and cultural identity leads to closer family bonds when this language is used.

As noted earlier, those with ASD often face social and communicative challenges. For instance, children with ASD can have difficulty with emotion perception (Uljarevic & Hamilton, 2013), making and maintaining friendships (Calder, Hill, & Pellicano, 2013), and achieving intimacy in sibling relationships (Kaminsky & Dewey, 2001). Given these
Parent perspectives on autism and bilingualism challenges, it may be especially important that children with ASD are able to benefit from the high quality affective, social and linguistic input that their parents’ native language might afford.

In sum, existing findings of no harmful effects of bilingualism for children with ASD seem to have little impact on parents' attitudes towards bilingualism. Moreover, research is necessary to determine whether parents’ native languages may play a role in supporting family relationships. Although prior qualitative studies have compared their findings with those of the literature addressing heritage maintenance issues in TD children (Yu, 2013), no qualitative work has examined this issue directly. No research, therefore, has attempted to directly determine how the experiences of bilingual families with a child with ASD differ from those of other bilingual families, and whether the effects of bilingualism (both for the child and family relationships) are comparable for families with a child with ASD and families with a TD child.

The present study aimed to address these gaps by investigating the following research questions:

1. What are the factors that influence bilingual parents’ decisions regarding their language practices with their child with ASD?

2. To what extent is the decision to speak / not speak a minority language influenced by factors such as family bonds, heritage and community cohesion?

3. What do bilingual parents feel have been the outcomes of the decisions they have made regarding their language practices with their child with ASD?

4. How do these influences and outcomes differ from those of bilingual parents of TD children?
Parent perspectives on autism and bilingualism

Method

The study took a qualitative approach, involving semi-structured interviews with bilingual parents of children with and without ASD.

Participants

Participants were 17 bilingual parents (4 fathers; 13 mothers) of a child with ASD and 18 bilingual parents (4 fathers; 14 mothers) of a TD child, recruited through local schools, support groups, a database of participants who had taken part in a prior study (Fletcher-Watson et al., 2015) and word of mouth. Inclusion criteria were that participants should be a bilingual parent with either a typically developing child or a child with a diagnosis of ASD between the ages of three and ten years old. This age range was chosen so that children would be old enough to have received a diagnosis of ASD but young enough for the issue of parental language choices to still be ongoing. There were no exclusion criteria concerning the level of the child’s exposure to a second language nor the age of first exposure. Two families in each group were resident in England, with all other participants residing in Scotland. One child in the ASD group and three children in the TD group were born outside the UK.

Parents of a child with ASD. Parents reported that they had a child with a best-estimate clinical diagnosis of ASD. Parents each spoke English with a high level of proficiency as well as at least one of the following languages: Brazilian Portuguese, Dutch, Finnish, French, Gaelic, Galician, German, Italian, Polish, Punjabi, Russian, Slovak, Spanish, Swedish, Urdu, Yoruba.

Parents of a TD child. One parent was a monolingual English speaker with a Finnish-speaking spouse. All other parents spoke English fluently as well as at least one of
Parent perspectives on autism and bilingualism

the following languages: Brazilian Portuguese, Catalan, Finnish, French, German, Italian,
Polish, Punjabi, Romanian, Shona, Spanish, Turkish, Urdu.

Though some of the parents interviewed had a monolingual, English-speaking partner, we chose to interview only the bilingual parent (and achieved this in all but one case). This was somewhat due to practical constraints – couples were often not able to be interviewed together due to childcare duties or scheduling difficulties. When interviewing only one parent, we felt it most beneficial to interview the bilingual parent due to their close proximity to issues such as cultural heritage and maintaining links with non-English-speaking extended family, and given that the bilingual parent would be the one to implement bilingualism were they to choose to do so.

The two groups were matched on children’s age, gender, birth order, and number of siblings. There were also no significant differences between groups in parents’ ethnicity, length of time in the UK, educational level, language spoken with live-in family members, and language acquisition history. There were no significant differences in the number of parents in each family who were bilingual and the number of parents in each family born outside the UK. These variables are displayed in Table 1 and Table 2.

[insert Tables 1 and 2 here]

Procedure

The study took a qualitative interview approach. One semi-structured interview (lasting from 1-2 hours) was conducted with each participating parent. Informed consent was gained from all parents. Parents were made aware that they had the right to decline to answer any question and that they could withdraw their participation at any time. Interviews took place wherever was most convenient for the parent; most often this would be the family
Parent perspectives on autism and bilingualism

home. A script containing open-ended questions was used to guide the interviews. Parents were asked about the factors that had influenced their decisions surrounding their child’s language environment, as well as what they felt the outcomes of their decisions had been. Parents were also asked for demographic data concerning the family as well as information on their child’s language skills. Questions taken from the Utrecht Bilingual Language Exposure Calculator (UBiLEC; Unsworth, 2013) were used to gather information about the child’s language environment. Interviews were all conducted with the same interviewer and took place entirely in English. One parent in each group elected to be interviewed with their spouse present.

Data Analysis

Interviews were video or audio recorded and transcribed in their entirety by the first author. Pseudonyms were used throughout the transcripts to preserve anonymity. A process of inductive, thematic analysis (Krahn, Hohn, & Kime, 1995; Thomas, 2006) was then used to arrive at themes and subthemes for each group (TD bilingual and ASD bilingual) separately. Thematic analysis of this type is appropriate for exploratory studies taking under-researched topics as their focus, as the approach emphasises deriving themes from raw data rather than examining data through the lens of prior theories and assumptions. First, transcripts were annotated with first-level codes identifying common meanings (e.g. ‘parent identity’, ‘role of extended family’). These codes were then checked for internal coherence and lack of overlap by removing, splitting or combining codes if necessary. To confirm validity, 20% of the first-level codes were checked by a second-coder. The coder was given a selection of codes and a list of clusters of quotes and asked to match each code to a corresponding cluster. This resulted in 100% agreement.
Parent perspectives on autism and bilingualism

First-level codes were then grouped into mid-level subthemes and top-level themes in discussion with the last author. Initially, only first-level codes derived from the TD data were grouped into broader subthemes. The ASD group first-level codes were then assigned, where appropriate, to the subthemes derived from the TD data. Where this could not easily be achieved, new subthemes were created that were specific to the ASD group. This process reduced the impact of the fact that the researchers could not be blind to the group membership of the participants. The TD subthemes effectively acted as a model against which ASD group subthemes were assessed, permitting a more valid estimation of those issues which were pertinent only to the ASD group.

In the final level of analysis, subthemes were grouped into themes for each group separately. To further increase validity of the analysis, member checks were then conducted by inviting all participants to give their opinion as to whether the codes, subthemes and themes accurately reflected their experiences. Those parents who responded indicated that they were satisfied with the analysis. We first briefly report shared themes applicable to both groups and then explore in detail the issues raised only by bilingual parents of children with ASD.

Results

Language Exposure and Language Proficiency

The language the interviewed parents used to communicate with their children for both groups and the children’s level of proficiency in English and the minority language for the ASD group are displayed in Figures 1, 2 and 3.

[insert Figures 1, 2 and 3 here]
Parent perspectives on autism and bilingualism

Shared (TD and ASD) Themes Emerging from Qualitative Data

Three shared themes arose from the interviews: effects of bilingualism for the child, child and family factors, and societal and cultural factors (see figure 4).

[insert Figure 4 here]

1. Effects of bilingualism for the child. Parents in both groups believed bilingualism confers a number of advantages. Beneficial effects mentioned included broadening the speaker’s mind to different perspectives and cultures, allowing them to: ‘see things from different perspectives. And to be aware that there are other options, other ways of approaching things.’ (Chiara; TD). The increased cultural as well as linguistic awareness associated with bilingualism was said by parents from both groups to help make children more aware of the diversity in the world.

In addition, many parents believed that bilingualism positively influences brain and general intellectual development: ‘Intellectually I think it’s good for him… I think he’s very good at understanding abstract notions, he’s very good at thinking about complex things.’ (Mario; TD). This positive influence was also referenced by parents in the ASD group: ‘I suppose the associated benefits of bilingualism - having better thought, problem solving skills, lateral thinking, that sort of thing [...] We were hoping that they will actually, rather than hinder, they were going to help his mental abilities.’ (Alasdair; ASD). Parents also believed bilingualism to be beneficial for their child’s future, particularly in terms of getting ‘more doors open’ for their education and ‘job prospects’. Parents of children with ASD additionally referenced several benefits not mentioned by parents of TD children. These
Parent perspectives on autism and bilingualism

benefits related to the ways in which bilingualism could positively influence ASD-specific
traits, and are discussed further below.

Despite the advantages cited, parents did not necessarily regard bilingualism to be
wholly positive for their children. A few parents of TD children expressed concern that a
bilingual environment may have slightly delayed their child’s language development, though
even this could be placed in a broader context of positive effects: ‘The advantages are really
fundamental, and they are forever. Whereas the disadvantage was only at the beginning.’
(Mario; TD). The impact of language delay was harder to ignore for parents of children with
ASD, who often expressed that a bilingual delay would amplify delays already present due to
ASD. For example: ‘I thought if bringing them up bilingually delays language development
anyway, then no, that would be even worse for him, if he's already delayed in his language.’
(Gerdi; ASD)

Both groups of parents, then, referenced the benefits of bilingualism while
acknowledging its potential to delay language development. For the parents of children with
ASD, this concern over the linguistic development of their child was harder to ignore.

2. Child and family factors. The child’s motivation was influential in impeding or
facilitating bilingualism. That is, for both groups, parents found it easier to implement
bilingualism if the child showed an interest in the minority language, and more difficult if the
child did not. On one hand: ‘there was absolutely no signs, you know, she just wasn’t
interested and after a while it was just like, 'why do I bother?', it's not worth it.’ (Gilles; TD)
and on the other: ‘he’s got that interest, that desire and that drive so therefore we’re just
using it as much as we can’ (Nazneen; ASD). The child’s lack of motivation emerged as a
stronger issue for parents in the TD group than the ASD group. References to motivation in
the ASD group tended to relate to the presence of motivation on the part of the child, with
parents in the TD group more often reporting a problematic lack of motivation. This may
Parent perspectives on autism and bilingualism

perhaps be due to reduced peer relationships amongst the children with ASD, given that parents in the TD group sometimes linked a lack of motivation with the child starting school and becoming immersed in an English language peer setting, ‘The main switch came at about school age, and before that she was far more likely to answer me back in German. All of sudden she decided, that is my language, and that is your language’ (Anke; TD).

In addition to the child’s characteristics, parents often felt that their family set-up contributed to making bilingualism trickier. For instance, where applicable, both groups reported that being the only minority language speaker in the household was challenging. Similarly, the parents’ own comfort with English had an impact on the level of importance they gave to bilingualism. While some parents felt at ease with English and as such found it ‘natural’ to speak it with their child, others felt more at ease speaking to their child in the minority language: ‘I couldn't imagine using any other language than my own. I didn't really think much about it to be honest, I didn't really have an alternative, because it was the natural thing to do.’ (Chiara; TD). Even for parents who felt highly proficient in English, the minority language was often described as facilitating the expression of emotion: ‘the emotional language is Italian.’ (Marina; ASD).

The majority of parents in both groups also reported that maintaining relationships between their child and the extended family was a key contributor to their desire to raise their child bilingually. For example: ‘I think that being exposed to Portuguese and English made Erico more welcoming of my mum and sister, because I can see he knows it's not English - they're speaking different. And he doesn't mind.’ (Adelaide; ASD). Parents of children with ASD additionally spoke of the role of bilingualism in maintaining child-parent relationships, an issue that was not strongly raised by parents of TD children. This issue is discussed further below.
Parent perspectives on autism and bilingualism

Both groups, then, reported factors such as the child’s motivation, the parent’s comfort in each language, and the languages spoken by other family members to be important influences.

3. Societal and cultural factors. Many parents in both groups described their native language as being connected to cultural heritage and feelings of identity and belonging:

‘Shona [a Bantu language mainly spoken in Zimbabwe], I think, gives me great identity, because it’s the language of my parents, and grandparents and then the people before them’ (Lydia; TD). Parents also reported wanting their children to share in this identity and many parents described how teaching the minority language to their children was entwined with communicating their cultural identity: ‘It would be very important for me, that she would be able to speak Italian, because of course, this is my first language, the heart language, and home language.’ (Marina; ASD). The minority language was described by some parents as a part of their legacy, with parents expressing that they would like to pass the language on to future generations. One parent in particular felt that passing on their language to their child was an important way of passing on a connection to their minority community: ‘we were both brought up in minority language communities, myself as Gaelic language speaker and my wife as a Galician speaker. So we were both very connected to our languages in terms of the community so we did want our children to speak those languages.’ (Alasdair; ASD)

Parents in the TD group discussed the importance of English for integrating into UK society. In particular, these parents valued English as a tool for both succeeding at school and for developing peer relationships: ‘[English] is what you want them to become strong in, so that they can do well in their education’ (Amarleen; TD) and ‘He’s been able to establish friendships, and just kind of have a great social life as well [...] it hasn’t left him out of groups as well, social groups.’ (Nusrat; TD). While parents in the ASD group often mentioned that living in an English speaking country was a motivation for exposing their
Parent perspectives on autism and bilingualism

child to English, only one parent explicitly made reference to English as a tool for allowing
their child to integrate in an educational setting.

Parents in the TD group also reported feeling the pressure of the views of family,
friends and society. Some parents, for instance, encountered negative attitudes from family
and friends for not raising their child bilingually: 'there's almost always this like, a negative
thing of, oh you've got your child in the UK, and you didn't bother to teach them Shona, and a
lot of people don't understand how that's possible' (Lydia; TD). Parents also felt the pressure
of negative societal attitudes towards bilingualism: 'people don't always like it when we speak
openly and I think people feel that we show a lack of respect by speaking in another
language.' (Andreea; TD)

These issues of cultural and social integration were not raised in the same way by
parents of children with ASD. Instead this group emphasised the role of professionals, which
is discussed further in the next section.

Experiences Unique to Parents of Children with ASD

The preceding summary illustrates that many issues influencing the decision to raise a
child bilingually, or not, were common to parents with and without a child with ASD.
However, within the shared themes described above, parents in the ASD group sometimes
expressed different or additional views to those put forward by parents in the TD group.
Further, there were some issues that were only raised by the ASD group that did not fit into
the subthemes developed for the TD group. These issues were grouped into a single theme:

Constraints imposed by ASD. We shall first consider this theme before turning to those
shared subthemes expressed differently by the two groups. Experiences unique to parents of
children with ASD are illustrated in figure 5.
Parent perspectives on autism and bilingualism

[insert Figure 5 here]

1. Constraints imposed by ASD.

a. Harmful interactions between bilingualism and ASD-specific difficulties. In addition to believing that bilingualism might amplify language delays already present due to ASD, some parents also believed that bilingualism would be an added burden for their child’s already limited cognitive resources, resulting in confusion and interfering with their child’s capacity to acquire any language at all: ‘I’m scared of putting in too much confusion, and he doesn’t understand anything at all. So, that’s why I just said, right OK, English and that’s it.’ (Yemisi)

As a result of these concerns, many parents felt a shift to monolingualism was the only option: ‘at the beginning it was important, then suddenly it's obvious that David's got some speech difficulties, so it went between what I wanted, which was him to be bilingual, and what was necessary for him’ (Baptiste). Indeed, 8 of the 11 parents who mostly or entirely used English to communicate with their child with ASD reported reducing their child’s exposure to the minority language after the onset of concerns about their child’s development. For some, this resulted in disappointment at having to sacrifice the minority language: ‘I wanted her to communicate with Polish family and with people here. But now, people around her are more important, because I want her to be able to express her needs precisely to them.’ (Agata) and ‘I really, really, want it, I always want it. But […] it couldn't be now, I will have to wait a few years to expose him to another language.’ (Adelaide)

Other parents, however, felt that the issue of bilingualism was eclipsed by greater concerns relating to ASD: ‘I don't care. I just wish she would speak, you know.’ (Caroline) and ‘with autism, it's much more other difficulties, other sort of bigger issues.’ (Veronika)

One key factor that influenced parents’ attitudes towards bilingualism was their child’s verbal ability. Contrast this quote from a parent of a more able child: ‘it seems pretty
Parent perspectives on autism and bilingualism

easy - you can see that from a child with autism, and a neurotypical way, that yeah, I think
they're just little sponges really' (Aurelie), with this alternative view point: 'for any kid that's
like David or worse, when it comes to communication, no, I don't think it's a good idea to try
several languages. It's hard enough with the single one.' (Baptiste)

Thus parents seemed to regard the child’s verbal ability, rather than an ASD diagnosis per
se, to be the key factor in determining whether or not a child should be brought up bilingually
(see Figure 2 for a representation of the relationship between the children’s verbal ability in
English and their language exposure). One parent also expressed that it may be inadvisable to
raise a child with ASD bilingually, regardless of language ability, if they experience
difficulties with flexibility: ‘it must be difficult switching from one setting to a different
setting and switching a language from one setting to another setting, so, it's probably more
difficult for them.’ (Agata). This was echoed in another parent’s comments on the relationship
between her son’s desire for routine and the potential effects of using more than one
language: ‘if you add in anything that is strange to his routine, it disrupts the whole day, so,
in that sense I'm thinking if I add in another language, what do I get?’ (Yemisi)

b. Burden of bilingualism for family functioning. In addition to the negative effects
of bilingualism for the child, several parents felt that bilingualism would be an additional
burden for the family as a whole: ‘there are so many challenges that you're going through,
and I don't know how many parents go through adding an additional language’ (Yemisi).
Indeed, many parents felt that they needed to ‘keep things simple’ for their child and that
maintaining two languages whilst doing so would be too much of a challenge for them:
‘everything is simplified down: we use a lot of repetition, we're very slow, we use key words
[...] if you're doing that, your other languages start to fade out because that again is just
adding layers of complexity.’ (Caroline)
Importantly, parents’ reliance on English was further exacerbated by a lack of bilingual ASD interventions and resources. ASD interventions were only delivered in English, and so parents found it more pragmatic to build on this language: ‘all his interventions were in English, so it made sense for us to reinforce that, rather than try and introduce another word’ (Neelam).

As such, parents often felt that their child’s difficulties due to ASD rendered bilingualism an impossibility, with many parents expressing that their child’s challenges eclipsed any aspirations they may have to raise their child bilingually.

2. Subthemes expressed differently in TD and ASD groups.

a. Societal and cultural factors: The influence of others. As noted above, both groups reported issues which were clustered into a subtheme called the Influence of Others, contained within the broader theme of Societal and Cultural Factors. Within this subtheme differences were apparent, with parents of TD children citing the influence of society, family and friends while parents of children with ASD referenced professional opinion.

The majority of parents did not seek or receive any professional advice. Of the seven parents who did, however, three experienced a 'general negativity' towards raising children with ASD bilingually and were explicitly advised to provide a monolingual, English-only environment for their child: 'a lot of people we took advice from suggested that it would be better to concentrate on one language, to avoid making things confusing.' (Zahid). For some families, this advice to speak only English was in stark opposition to what they regarded as the best course of action for their child: ‘We were told by doctors to switch to English. But we didn’t want to do that because we didn’t want him to go back to not understanding anything […] we thought it might be quite traumatic for him, to suddenly go from
Parent perspectives on autism and bilingualism
understanding, his limited understanding as it was, to a completely new language, as if these two parents he knew all his life had just left and switched to something else.' (Alasdair)

Four families, however, were advised that bilingualism would not be harmful for their child: 'she said it's not going to make any impact if we start speaking English to him, he's not going to learn language better or faster [...] She told us to just keep doing what we're doing, so just use Polish at home.' (Katarzyna). Despite this positive advice, some parents found it difficult to reject the belief that bilingualism would have a negative impact: 'it was actually hard to accept that 'cause it was like, his brain's not working properly, and he's got delays, and why are we not making things easy and saying all in English?' (Tomasz)

Ultimately many parents felt that there was a lack of information available concerning the effects of bilingualism for children with ASD and for some parents this led to uncertainty and a mistrust of bilingualism: 'I would try and do it if it's going to be beneficial but, for me, the fact that I don't even know what to expect, it's just been scary, and I just didn't even bother at all.' (Yemisi)

b. Effects of bilingualism for the child: benefits. As noted earlier, both groups commented on the effects of bilingualism for the child, including its associated benefits. Within this subtheme of the benefits associated with bilingualism, parents in the ASD group additionally referenced several positive effects that were of particular relevance to children with ASD. Despite the sometimes negative professional opinions described above and recurrent concerns from parents that bilingualism would negatively influence their child’s development, some parents believed that bilingualism could have positive effects on skills that those with ASD often find challenging. For instance, one parent felt that bilingual exposure was a way of providing learning opportunities for their child, and that this would benefit them in the long-term: ‘by not giving him the same monotonous routine every day, by
Parents identified communication as a particular skill that could be enhanced by bilingualism. One parent, for instance, described how processing instructions in two languages helped their child’s understanding: ‘if I tell her a multi-step instruction of what I need her to do, say four steps, I will then ask her to repeat it back to me in English, which gets her to process the instructions in a different way [...] and that seems to help her with the understanding.’ (Isla). Another parent felt that the communicative demands associated with interacting with non-English-speaking relatives had a positive impact on their child’s communication: ‘I think the main, positive thing of being exposed to two languages, is that he’ll go a bit further to make himself understood. Usually he would try and show my mum things [...] just to make her understand.’ (Adelaide)

In addition, several parents felt that exposure to languages other than English may serve as soothing auditory stimulation for their child: ‘he seems to enjoy really fast verbal interactions that people have in those languages, so we often find him deliberately clicking on clips that are in a different language.’ (Neelam). A sub-set of parents, then, believed bilingualism to be associated with benefits for children with ASD in particular, with bilingualism even providing opportunities to hone abilities that children with ASD might find difficult. It is worth noting, however, that some of the parents who identified ASD-specific benefits of bilingualism also expressed some reservations about the effects of bilingualism on the language development of children with ASD. These tended to be parents of children with lower verbal skills; in contrast, three out of the four parents who considered their child to be high-functioning felt that bilingualism brought no disadvantages.

c. Child and family factors: family characteristics and relationships. In addition to
Parent perspectives on autism and bilingualism

Positive effects for the child, parents of children with ASD also often talked of the benefits of bilingualism in terms of maintaining parent-child bonds. As already discussed, both groups raised issues relating to family characteristics and relationships, but within this subtheme, the particular issue of parent-child bonds arose for parents in the ASD group only. For these parents, the minority language was often associated with the expression of affection between parent and child: "especially when he wants to express his fondness to me [...] he deliberately chooses Russian words when he says, for example, 'give me a cuddle'" (Veronika). Parents also reported feeling an enhanced relationship with their child when using the minority language: "the native languages are much closer to home, family, community, so for me that's very important that I'm speaking to him in that language because I feel much closer to him." (Alasdair), and this also applied when the child themselves was non-verbal: "if me speaking Punjabi to him sometimes is calming, or soothing [...] I'll carry on doing it" (Neelam).

Conversely, English was often viewed as a practical tool to be used when trying to elicit a response from the child: "If I'm talking about something she wouldn't understand in English anyway [...] I would maybe just talk to her in my own language, but not if I want to get something I want." (Alica). Despite the predominantly practical, communicative function of English, some parents reported that speaking only English with their child could be a barrier to successful communication, as they did not want to pass on grammatical mistakes: "Sometimes I would like to say something to her and sometimes I stop, because [...] sometimes I'm worried to say things incorrectly, so that she learn things incorrectly". This parent went on to say, "I find it quite frustrating because I would like to say more things to my daughter, and, communicate more in my language" (Marina).

Summary
Parent perspectives on autism and bilingualism

All in all, then, parents of children with ASD shared many of the same experiences and views as parents of TD children, in terms of believing bilingualism to entail both benefits and disadvantages, experiencing certain child and family characteristics as facilitators of, or impediments to, bilingualism and appreciating the links between language and cultural heritage. Parents of TD children additionally valued English as a means of fitting into UK society and experienced conflicting attitudes of family and society towards bilingualism.

Some additional themes only emerged from parents of children with ASD. They expressed trepidation that exposure to two languages might be detrimental not just to their child’s language but also to cognitive and behavioural development. The presence of challenges associated with ASD meant that these parents sometimes experienced bilingualism as a burden. Parents of children with ASD also encountered varied professional advice that was sometimes at odds with their own assessments of their child’s needs. Despite concerns, some parents also felt that bilingualism may provide advantages in communication for children with ASD. Finally, several parents emphasised the role of the minority language in maintaining affectionate child-parent relationships.

Discussion

This study aimed to explore what bilingual parents of children with ASD feel the influences upon and outcomes of their decisions regarding their children’s language environment are, and how these differ from those of parents of TD children. Parents of children with ASD shared many of the same experiences as bilingual parents of TD children, though additionally felt that bilingualism would prove both challenging for the family and harmful for their child. Despite this, parents (especially those with children of high verbal ability) identified a number of benefits of bilingualism that could be particularly salient for children with ASD.
Parent perspectives on autism and bilingualism

Our findings extend those of the prior literature by showing that parents of children with limited verbal ability tend to experience greater anxiety concerning bilingualism - indeed, most of those raising their child entirely monolingually in our sample were parents of children of lower verbal ability. This link between verbal ability and language choices did not emerge as a full theme, however, and instead was just one of many ASD-specific constraints which was apparent in parents’ decision-making. Nevertheless, the findings suggest that the adoption of an entirely monolingual environment may be more likely for parents of children with low verbal ability, and further shows that the characteristics of the child are an important determiner of parents’ choices. Our findings complement those of Hambly and Fombonne (2014) who found that children’s vocabulary in a second language was related to their dominant language skills and that children with lower dominant language skills tended to experience greater reductions in exposure to a second language than those with higher skills. Our study adds to these previous findings by demonstrating that parents of children with lower verbal ability make a conscious decision to restrict exposure to a second language due to concerns about negative consequences for their child’s language development.

The advice of professionals also had an impact on parents’ decision-making. In contrast to previous studies, a substantial proportion of parents were advised that bilingualism would pose no threat. It may be that, in the UK at least, attitudes of professionals towards bilingualism are becoming more favourable. The advice given may also depend on the set-up of the family. Families who received pro-bilingual advice were predominantly of nationalities with a large community in Scotland (such as Polish), and it is possible that professionals felt that maintaining the minority language in these cases would be beneficial to families’ place in the wider cultural community.

Another important influence on parents’ decision-making was the role of the minority language in maintaining family bonds. This implies that restricting input to only English may
Parent perspectives on autism and bilingualism mean sacrificing the warmth and emotional closeness associated with the minority language. Indeed, some parents indicated that an English-only environment was a barrier to communication with their child. It is possible that parents of children with ASD can feel an increased responsibility to correctly model language for their child. As such, when communication does not occur in their native language, reduced interactions with their child may result due to fear of passing on errors. Exposure to the minority language, then, may have a beneficial effect on children with ASD and their family, providing high quality social, as well as linguistic input.

This is the first study in a UK context to demonstrate the role of parents’ native languages in facilitating positive parent-child relationships in families with a child with ASD. Indeed, this role may be of particular relevance in countries such as the UK, in which there is only one majority, community language (English) alongside a heterogeneous range of minority languages, the speakers of which tend to be relatively few and somewhat dispersed (Office for National Statistics, 2011). This situation, in which bilingualism is somewhat rare, is in stark contrast to that of countries (such as China) where several official community languages are spoken, and to that of countries (such as the US) with large bilingual communities. In such countries, bilingualism is more the norm and therefore may not be connected to preserving heritage and identity in the same way as in the UK. The limited literature addressing intergenerational heritage language transmission in the UK suggests that maintenance of the minority language is associated with maintaining family and community bonds (Mills, 2001). The present study demonstrates that this extends to families with children with ASD.

In terms of the outcomes of their decisions, parents who exposed their child to two languages often felt their child acquired skills in more than one language. This was true for children of both higher and lower verbal ability, possibly suggesting that those with ASD
Parent perspectives on autism and bilingualism across a range of verbal capabilities may be able to become bilingual to some degree. This complements the finding of Hambly and Fombonne (2014), that recent exposure to a second language for children with ASD is related to the child’s ability in that language, and that even children with lower verbal ability can gain some vocabulary in a second language.

Moreover, a number of positive outcomes of bilingualism for the child were identified and, in addition, our findings point towards possible mechanisms behind such outcomes. These mechanisms include allowing the child to process spoken language in different ways in order to aid comprehension, and giving the child training in communication through tackling the communicative demands of interacting in their second language. Furthermore, while parents of children with lower verbal ability were less likely to think of bilingualism as wholly beneficial, these parents still recognised benefits. Further research is necessary to establish whether parents’ intuitions that these benefits may be present in children with lower as well as higher verbal ability holds true.

Not all the influences and outcomes identified were unique to families with a child with ASD. Parents in both groups found their comfort in each language, support from other minority language speakers and the child’s motivation all to impact upon their decision-making. While important for parents of TD children, for parents of children with ASD these influences were dwarfed by ASD-specific challenges, indicating that bilingualism is experienced as particularly challenging for parents of children with ASD.

Furthermore, whilst parents of TD children valued the minority language for its link to heritage, they did not often make reference to parent-child bonds. This may be because maintaining an affectionate, natural way of communicating is of increased importance to parents of a child with ASD, given their child’s social and communication difficulties. As such, the beneficial impact of bilingualism on family relationships might be particularly salient for families of children with ASD.
Parent perspectives on autism and bilingualism

Parents of TD children sometimes felt bilingualism may have led to linguistic delay. Interestingly, while concerns about delay strongly motivated parents with a child with ASD not to raise their child bilingually, unlike parents of TD children, those who did raise their child bilingually did not feel bilingualism had contributed to delay. This may have been due to reassurance from professionals, or else may indicate that parents who raise their child with ASD bilingually tend to have strong prior beliefs that bilingualism is not harmful, something that may not be the case for parents of TD children.

Limitations

Parents tended to be highly educated, had often resided in the UK for many years and were generally very proficient in English. These factors may have contributed towards bilingualism being experienced as an ideal rather than a necessity by some parents. Interviews took place in English due to being conducted with a monolingual English-speaking interviewer. This meant that the sample was limited to those proficient in English and the experiences of parents with lower English proficiency could not be explored. The use of English may have also affected the parent’s level of comfort during the interview. Furthermore, a heterogeneous range of languages were included in the sample and therefore the experiences of particular communities could not be explored. Many of the parents interviewed had a monolingual spouse though the attitudes of this spouse were not sought directly. It is possible that a monolingual parent may hold different attitudes towards bilingualism than a bilingual parent. For example, monolingual parents may value providing an English-only environment given the increased opportunities this would provide to bond with their child in their native language. Similarly, monolingual parents may not want to be excluded from their bilingual partners’ child-directed communication if this communication takes place in a language other than English. Monolingual and bilingual
Parent perspectives on autism and bilingualism

parents of children with ASD may hold different views on the potential linguistic
consequences of bilingualism for their child. For example, it is not known whether the
monolingual spouses of the interviewed parents in our study who were raising their child with
ASD bilingually were also re-assured that bilingualism did not cause delay. Further, any
differences may also interact with the child’s diagnostic status, with the monolingual parent
perhaps having a stronger influence over the language practices adopted with the child when
the child in question has been diagnosed with ASD. In addition, language barriers for the
bilingual parent may mean that the monolingual parent is the one who deals directly with
medical professionals. In this case, the monolingual parent may exert more influence in the
context of parent-professional relationships than the bilingual parent, something which may
be especially problematic if the bilingual parent is the child’s main caregiver.

It would be important in future studies to examine how monolingual as well as
bilingual parents of children with and without ASD make decisions about their children’s
language environment.

Clinical Implications

The notion that bilingualism is inadvisable persists amongst some professionals. It is
vital, therefore, that professionals are informed of the existing evidence of no harmful effects
of bilingualism. The present results also point to the importance of considering factors such
as the family set-up, the child’s prior language exposure and family relationships when
making clinical recommendations. In particular, our findings point to the impact of the
child’s verbal ability upon parents’ language choices. Parents of non-verbal children and
children of lower verbal ability are much more likely to show concerns about potential
negative consequences of bilingualism and to ultimately restrict their child’s input to one
language. Clinicians should be aware of this tendency and consider the level of verbal ability
Parent perspectives on autism and bilingualism of the particular child when giving clinical recommendations. Families would also benefit from greater assistance in the implementation of bilingualism: the availability of bilingual resources and interventions for children with ASD would help families experience bilingualism as less of a challenge.

Conclusions

Parents of children with ASD continue to have concerns regarding bilingualism, yet indicate several potential benefits. These include high quality linguistic and social input and a positive effect on family relationships. It is essential to build a greater evidence base to enhance family decision-making in this area. Our results point towards the importance of considering factors such as family coherence and community integration, as well as language development, in future empirical research in this field.
Parent perspectives on autism and bilingualism

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Parent perspectives on autism and bilingualism

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Parent perspectives on autism and bilingualism


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Parent perspectives on autism and bilingualism

**Figure captions**

Figure 1: Children’s language exposure from the interviewed parent for ASD and TD groups.

Figure 2: Relationship between language exposure from the interviewed parent and English proficiency for the ASD group.

Figure 3: Relationship between language exposure from the interviewed parent and non-English language proficiency for the ASD group.

Figure 4: Shared themes and subthemes for ASD and TD groups.

Figure 5: Theme and subthemes unique to the ASD group and shared subthemes expressed differently by the ASD group.

Table 1: Child characteristics for both groups

Table 2: Parent characteristics for both groups
Parent perspectives on autism and bilingualism

Supplemental material description

Interview script: A list of open-ended questions used to guide the semi-structured interviews.
Non-English language exposure range: 5% to 30% of the time (ASD); 5% to 20% of the time (TD).

Non-English language exposure range: 50% to 100% of the time (ASD); 70% to 100% of the time (TD).
Note. All TD sample were fluent apart from one child with ‘short phrases’ in the ‘majority non-English’ group. This child was 3.5 years old and having speech and language therapy. The child was not being assessed for an ASD diagnosis.
Note. Children exposed to the minority language were exposed from birth. Two children had never been exposed to the minority language. 8 parents reduced minority language exposure after ASD-related concerns.
ASD-specific themes and subthems:

Constraints imposed by autism

- Harmful interactions between bilingualism and ASD-specific difficulties
- Burden of bilingualism for family functioning

Shared subthems expressed differently:

- Societal/cultural factors
- Effects of bilingualism
- Child/family factors

- The influence of others (professionals)
- Benefits (effects particular to children with ASD)
- Family characteristics and relationships (parent-child bonds)
Table 1

**Child characteristics for both groups**

<table>
<thead>
<tr>
<th></th>
<th>ASD (n=17)</th>
<th>TD (n=18)</th>
<th>t (33) = -0.44, p = 0.66</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age (SD) [range]</td>
<td>6.45 (1.69) [3.58-10.92]</td>
<td>6.71 (1.88) [3.50-10.58]</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>male: female 10:7</td>
<td>10:8</td>
<td>X² (1) = 0.04, p &gt; 0.05</td>
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<tr>
<td>Birth order</td>
<td>Only 6</td>
<td>6</td>
<td>X² (4) = 1.33, p &gt; 0.05</td>
</tr>
<tr>
<td></td>
<td>Youngest 2</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Middle 1</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Oldest 8</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Twins 0</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>No. of siblings:</td>
<td>0 6</td>
<td>6</td>
<td>X² (3) = 1.23, p &gt; 0.05</td>
</tr>
<tr>
<td></td>
<td>1 6</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>2 4</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>3 1</td>
<td>0</td>
<td>-</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>ASᵃ 1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>ASD + DSᵇ 1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>ASD + GDDᶜ 1</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>ASD 14</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Mean age at diagnosis (SD) [range]</td>
<td>3.43 (1.69) [1.5-9]</td>
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<tr>
<td>Schooling</td>
<td>Mainstream 6</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Special 10</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td></td>
<td>Home schooled 1</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

ᵃAS=Asperger syndrome  
ᵇDS=Down syndrome  
ᶜGDD=Global developmental delay
Table 2

Parent characteristics for both groups

<table>
<thead>
<tr>
<th>Interviewed parent characteristics:</th>
<th>ASD (n=17)</th>
<th>TD (n=18)</th>
<th>( \chi^2 (3) = 1.74, p &gt; .05 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White European</td>
<td>12</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Pakistani/Indian</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>African</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>White and African</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Mean length of time in UK (SD)</td>
<td>13.79</td>
<td>9.94</td>
<td>( t(28) = 1.90, p = .07 )</td>
</tr>
<tr>
<td>years</td>
<td>(6.59)</td>
<td>(4.45)</td>
<td></td>
</tr>
<tr>
<td>Education</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Postgraduate</td>
<td>6</td>
<td>7</td>
<td>( \chi^2 (2) = .99, p &gt; .05 )</td>
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<tr>
<td>Undergraduate</td>
<td>7</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>A levels/Highers</td>
<td>4</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Language spoken with live-in family members</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Mostly English</td>
<td>11</td>
<td>11</td>
<td>( \chi^2 (1) = .05, p &gt; .05 )</td>
</tr>
<tr>
<td>Mostly non-English language</td>
<td>6</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>English acquisition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Raised with English as community but not home language</td>
<td>3</td>
<td>1</td>
<td>( \chi^2 (3) = 2.53, p &gt; .05 )</td>
</tr>
<tr>
<td>Raised with English as home but not community language</td>
<td>0</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Raised with English as home and community language</td>
<td>3</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Acquired through school and moving to UK</td>
<td>11</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Minority language acquisition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Raised with minority language as home but not community language</td>
<td>3</td>
<td>2</td>
<td>( \chi^2 (1) = .31, p &gt; .05 )</td>
</tr>
<tr>
<td>Raised with minority language as home and community language</td>
<td>14</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Couple characteristics:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Born outside UK</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>One parent</td>
<td>9</td>
<td>8</td>
<td>( \chi^2 (2) = .55, p &gt; .05 )</td>
</tr>
<tr>
<td>Both parents</td>
<td>7</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Bilingual</td>
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<td>1</td>
<td>2</td>
</tr>
<tr>
<td>-----------</td>
<td>---------</td>
<td>----</td>
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<td>One</td>
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<tr>
<td>Both</td>
<td>9</td>
<td>9</td>
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</tbody>
</table>

$X^2 (1) = .30, \ p > .05$
Parent perspectives on autism and bilingualism

**Interview Script**

**Attitudes towards bilingualism and autism**

- What is raising a child with autism like for you?
  *Prompt: What have you found difficult/rewarding?*
- How important or unimportant is it to you that your child speaks more than one language?
- What do you think the effects of being exposed to more than one language might be?

**Influences upon the languages used to speak to child**

- Tell me about what it has been like for you to bring up a child with autism in a household with more than one language?
- What have been the main influences on the language(s) you use to speak to your child?
- Have you ever considered taking a different approach?

**The importance of each language**

- Which languages do you feel are most important to you?

**Advice**

- What advice have you received (both professional and otherwise) about raising your child to speak more than one language?
- Has the advice you’ve received influenced the language(s) you use to speak to your child in any way?
- What information have you received about this topic?

**Experience of diagnosis**

- Describe for me your experience of getting a diagnosis of autism for your child.
- Do you feel that the process of getting a diagnosis was affected in any way by your child being in a multilingual household?

**Outcomes**

- Please tell me about what you feel the effects have been of the language choices you’ve made for your child.
- What have been the advantages and disadvantages of the language choices you’ve made?
Parent perspectives on autism and bilingualism

**Statements**

I'm now going to read to you some short statements, and I will ask you whether you agree or disagree with each one according to your experience.

- "It is important that my child speaks languages that relate to my religious beliefs/cultural background."
- "Raising a child with autism to speak more than one language is difficult."
- "The pace of my child's language learning has influenced the languages I use to speak to them."

**Closing questions**

- What advice would you give to other families raising a child with autism in a multilingual environment?
- What kind of information do you think would be useful for families raising a child with autism in a multilingual environment to know? *Prompt: What direction would you like to see research in this area take in the future?*
- Is there anything else you would like to add?

The survey presented in this Appendix appears courtesy of the authors.